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## Interactions between Psychological and Physical Aspects of CF: Follow up Annual Review Results

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**Aims** Patients with CF are now living longer lives and face a range of decisions, dilemmas, and emotions connected to gaining independence whilst also facing health changes. We wished to see how patients dealt with changes in physical health from a psychological perspective, particularly declines in $FEV^1$ or BMI.
**Methods** As part of on-going clinical work changes in $FEV^1$ and BMI were recorded between two annual review points. We examined how these changes related to responses on a psychological questionnaire (CFPsychQ).
**Results**
12 patient follow-ups
Patients aged 18 – 38 years at the 1st annual review
5 patients showed decline in $FEV^1$
3 patients showed decreased BMI scores
Where $FEV^1$ and/or BMI went down over the year, patients often showed increased worry about the future, anxiety, frustration, and depression. Feelings of being in control also frequently decreased. Changes in family involvement at this time had to be carefully negotiated; in two cases, the patient wanted less involvement despite poorer health.
Where $FEV^1$ and BMI increased, patients often recorded less worry about the future, less anxiety, and depression. They felt more in control. Patients may now also wish for less involvement from parents in their lives.
**Conclusion** With changing physical health, patients may begin to recognize their shortened life span or, feeling a need for independence, make a move away from the family home. A number of related emotions are also felt. Patients may need support from the psychological team in negotiating any moves towards further independence in the face of declining health.
Talking to patients at annual review and gaining their responses on the psychological questionnaire facilitates discussions about health, adherence to medication, family involvement, and the concomitant emotions.

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## Adults with cystic fibrosis experience of living with diabetes- an exploratory interpretative phenomenological analysis (IPA)

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Diabetes is a common complication of CF. The onset and diagnosis of Cystic Fibrosis Related Diabetes (CFRD) signifies the development of a second chronic illness.
*Aim*: the purpose of this study is to explore and describe the experience of living with a second chronic illness for adults with CF. There are currently no published studies in this area.
*Method*: A phenomenological approach was chosen in order to obtain a rich, in-depth detailed account of the experience of living with CFRD and its impact on daily life. Five adults with CFRD (4 male, mean age 32years, duration of diabetes 3-12 years, all insulin dependent) were recruited from this centre. Unstructured interviews took place, these were tape recorded and transcribed verbatim. The participants were encouraged to discuss freely and spontaneously their experiences, attitude, behaviour and feelings about living with CFRD. Data were analysed using the process of IPA. IPA recognises the research process as dynamic where one is trying to take an insider's perspective.
*Results*: Themes which arose from this analysis include: Managing the initial diagnosis of diabetes, managing the impact of diabetes on lifestyle, managing the treatments of diabetes, managing diabetes through changes in behaviour and limiting the impact of diabetes.
*Conclusions*: this has enabled participants to express in their own words what it is like to live with the burden of a second chronic illness. This study is ongoing however it is anticipated that these experiences will contribute to improvements in management of CFRD providing the CF team with a more holistic approach.

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## Fathers' Perspectives on Managing the Care of their Children with Cystic Fibrosis (CF)

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**Background** Little is known about fathers' involvement in their children's CF care as most research to date has been based on research from mothers' perspectives.
**Aims** To explore fathers' perspectives on managing the care of their children with CF with consideration to their involvement in daily care and factors that promote or inhibit their involvement. **Methods** Eight Irish fathers of preschool children with CF took part in audio-taped interviews in their own homes. Data were analysed using thematic content analysis. Rigour of the study was enhanced through the use of verbatim quotations, reflexivity and a decision trail of the research process.
**Results** Fathers believed they made an important contribution to the day to day care of their children with CF which might not always be recognized by their partners/wives or health care professionals who saw mothers as the primary care givers. Constrains on fathers' contribution to their children's care were identified, in particular their working hours and child age related difficulties. **Conclusion** The findings suggest a need for health professionals to support fathers through the illness management experience and to plan interventions that are inclusive of fathers' needs to enable them to care for their children in ways that take account of their particular contributions.

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## Psychosocial adjustment and coping in parents of children with cystic fibrosis: Preliminary findings

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**Aims:** This qualitative study explored the impact of cystic fibrosis and treatment on mothers of children with CF, current stresses experienced and coping strategies used by them. **Methods:** 10 mothers of children with cystic fibrosis participated in semi-structured interviews with a clinical psychologist. The interviews were tape-recorded, transcribed and analysed using Interpretative Phenomenological Analysis (Smith et al., 1996). **Results:** The following themes emerged from the data: a. Overall, mothers were well adjusted although for many of them their lives revolve around the child's illness. They seem to loose their own identity and assume the identity of the carer of a child with CF; b. they actively try and maintain a degree of normalcy at least at times when the child is not very ill; c. stresses experienced by these mothers included: illness-related (e.g. medical crises, nonadherence, mealtimes), Developmental and Social limitations. The most difficult issue to cope with was that mothers *see* a healthy child but *know* that the disease is progressing; d. protective factors for mothers included: increased family cohesion, established family routines, flexibility, and low marital conflict.**Conclusions:** Many families experience minimal disruption and find increased closeness in their combined efforts to care for a child with CF while other families are devastated and unable to cope effectively. It is necessary to support each family and parent individually on their unique way in coping with the disease.
**Reference** Smith J.A., Jarman M., and Osborn M. (1999). Doing interpretative phenomenological analysis. In M. Murray and K. Chamberlain (1999) *Qualitative Health Psychology. Theories and methods*. Sage Publications.